

Treatment of Childhood Cancer in Southern Nigeria: Parents Perspective

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Background: The care and treatment of a child with cancer is stressful for parents. Recognizing their challenges and addressing them are important strategies in aiding families cope with cancer therapy. **Objectives:** To ascertain the perspectives of parents on childhood cancer therapy and understand their challenges in order to devise effective ways of supporting them. **Methods:** This qualitative study was conducted between June and November 2018. Data were obtained through semi-structured interviews held with 27 parents whose children were being treated for various cancers at the Paediatric Oncology Unit of the University of Port Harcourt Teaching Hospital, Nigeria. **Results:** Respondents were 19 mothers, 2 fathers, and 3 couples. Their children were aged 11 months to 15 years. Majority of respondent knew the diagnosis of their children while few could only name the site of the tumour. While undergoing chemotherapy, refusal to eat, vomiting, fever, pain, and falling of hairs were symptoms parents perceived as most distressing, which also affected them negatively. Treatment related costs drained families' monthly incomes and were considered the major challenge to treatment compliance. Financial support and prayers received were much appreciated and helped them cope better with their child's therapy. **Conclusion:** Parents of children with cancer experience various stressors related to treatment. There is need to consistently offer them information regarding the side effects of cancer therapy and best ways of coping with them. They need to be supported in various ways to ensure compliance to their child's therapy.

Keywords: experience, parents, treatment of childhood cancer, Southern Nigeria

Introduction

Cancer is a leading cause of death for children, with 300,000 new cases diagnosed each year among children aged 0-19 years, while more than 90% of children with cancer live in low- and middle-income countries where they are four times more likely to die of the disease than children in high-income countries (WHO, 2018; Bhakta et al., 2019).

It has been suggested that childhood cancer be considered as a family disease, as it affects not only the child but also the family as a whole (Elcigil & Conk, 2010). When cancer is first diagnosed in childhood it is usually a shocker to the parents or primary caregivers (Witt et al., 2010; Renner & McGill, 2016; Eke, 2019). And after diagnosis, parents are expected to hastily understand a considerable amount of information related to the disease, assume new supportive abilities, as well as adjust their usual family roles or responsibilities to

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accommodate the exigencies imposed by the cancer treatment (Sultan, Leclair, Rondeau, Burns, & Abate, 2016). These parental modifications are often targeted at switching their focus from being parents to becoming the primary caregiver of a child with cancer.

The journey of cancer treatment is paved with numerous stressful experiences for the parents/primary caregivers, including among others, the physical, social, psychological, and economical challenges in coping with the new reality they found themselves in. This burden of care, a reflection of the undesirable events and difficulties brought about by the disease upon the members of the family, is related to the frequent and long treatments and hospitalizations, medical problems of the children, and is most experienced by mothers, who are often the primary caregivers (Elcigil & Conk, 2010; Saifan, Masa'Deh, Hall, & Collier, 2014). These experiences can be overwhelming and affect their quality of life (Elcigil & Conk, 2010; Naidoo et al., 2016; Turkoglu & Kılıc, 2012).

Primary caregivers have been reported to have adopted various strategies to help them cope with their situations (Elcigil & Conk, 2010; Njuguna et al., 2015; Kohlsdorf & Costa, 2012). Financial issues related to the treatment have been a major concern for caregivers, especially in resource limited settings (Renner & McGill, 2016; Njuguna et al., 2015; Israëls, Chirambo, de Kraker, Caron, & Reis, 2008).

In Nigeria, though childhood cancers constitute a smaller percentage of childhood illnesses compared with infectious and other non-communicable diseases, they impose a tremendous burden on patients and families as social support systems are often lacking (Brown, James, Ajayi, Ogun, & Oladokun, 2009; Akpan-Idiok & Anarado, 2014). This has led to many cases of abandonment of treatment and/or impoverishment of affected families. It is however not so in the more affluent countries of the world where health policies and insurance systems are in place to cater for children with cancer (Dowling, Yabroff, Mariotto, McNeel, Zeruto, & Buckman, 2010).

There is limited literature around the experiences of parents who have a child undergoing cancer treatment in Nigeria and existing ones are mostly on adult patients (Dowling et al., 2010; Yusuf, Adamu, & Nuhu, 2011). Therefore, this study was conducted to ascertain the perspectives of parents/caregivers on childhood cancer therapy and understand their challenges in order to devise effective ways of supporting them.

Subjects and Methods

The study was conducted at the University of Port Harcourt Teaching Hospital (UPTH), an 800-bedded facility and reference cancer centre located in Port Harcourt, and one of the two tertiary care hospitals in Rivers State, Southern Nigeria. With the National Health Insurance covering about 5% of the population, financing for childhood cancers in Nigeria is mainly through out of pocket payment (Onwujekwe, Hanson, & Uzochukwu, 2012).

Participants in this qualitative descriptive study were parents whose children were diagnosed with various cancers and had commenced treatment for at least three months prior to the study, at the Paediatric Oncology Unit of the UPTH, between June and November 2018.

They were mostly mothers (22) and few fathers (5). Both parents participated in the interviews in three occasions, giving a total of 27 participants. Among these respondents, 23 were married, 2 were single mothers, and 2 were widows. For 9 participants, their average monthly family income was below 50,000 naira (138 USD), while for others between 50,000-99,999 naira (138-277 USD) (7), between 100,000-200,000 naira (277-555 USD) (3), and 5 participants had more than 200,000 naira (555 USD). Among the children of these

participants, 13 were between 1 and 5 years of age, 7 were in the 6-10 years age bracket, and 4 in the 11-15 years age bracket. The most common malignancies affecting the children were leukaemias (9), nephroblastoma (5), rhabdomyosarcoma (3), and retinoblastoma (3).

Twenty-four semi-structured interviews were conducted in English or Pidgin English languages when parents brought their children for chemotherapy or follow-up visits and participation was voluntary. The interview form was composed of semi-structured questions designed to explore the experience of parents with the cancer treatment that their children were undergoing.

Bio data of respondents were obtained, while key topics of interviews included their knowledge of the child's diagnosis, symptoms and side effects of medication they found distressing, challenges to treatment compliance and perceived needs to cope better with their child's illness.

The interviews, which lasted about 45 minutes each, were recorded with permission and all recordings were transcribed by one researcher.

Inductive thematic analysis was used to analyse the data (Braun & Clarke, 2006). The data were transcribed verbatim; pseudonyms protected anonymity. After familiarization with the data, a list of concepts was formulated, similarities were noted and clustered into conceptual categories, and potential and final themes were identified (Braun & Clarke, 2006). Emerged themes capturing cancer-related stressors included cancer treatment/side effects, social challenges, and coping strategies.

Approval for the study was obtained from Medical Ethics Committee of the Hospital and informed consent was obtained from the parents who participated in the study.

Findings

The majority of parents (17) knew the diagnosis of their children, while four parents could only name the site of the cancer. One mother: "*my child has cancer of the blood*"; another mother: "*she has a cancer in her kidney*". Three mothers could not recall their children's diagnosis, one of them: "*the doctor said my son has something in his bladder*"; another mother: "*I can't remember what they said...*"

Most of the respondents reported that their children suffered from the side effects of the chemotherapy, which also affected them as caregivers, both physically as they were often tired, physically and emotionally as watching their child going through the whole ordeal was not easy.

Common side effects mentioned included vomiting, refusing to eat, weakness, pain, falling of hairs, and need for blood transfusion. Pain from numerous needle pricks were also mentioned by many mothers together with the side effects their children's therapies.

One Mother: "*... refusing to eat, which is worse on the days after chemotherapy is so distressful. He will be so weak and still refusing to eat. I don't like seeing him in that state. No amount of begging will make him eat, not even his favourite food*".

Parents stated that complying with treatment was very challenging, especially its financial aspect, which included among others cost of drugs, investigations, long hospital admission, and cost of feeding. Since the cancer treatment started, many families stated financial difficulties as it drained the family's monthly income, causing many respondents to borrow money from friends and relatives; some have sold their belongings to accommodate the child's treatment expenses.

The father of a two years old girl with leukaemia: "*... my daughter's treatment started about 6 months ago. I know that it has not been regular. Money is the problem, but am trying my best. I have borrowed from*

everyone I know. Still, we are far from the end of treatment. I may not have any other choice than to take my child away..."

How parents were coping with cancer therapy revealed that the various supports they received were important factors in helping them meet up with the exigencies of treatment. Supports received were mainly from family, church members, friends, and colleagues, while none benefited from any government support.

Mother of a five years old boy with nephroblastoma, who received her termination letter from her employer while she was caring for her sick child in the hospital: *"... after diagnosis was made we could not afford treatment and stayed home. But many months later, when my son could no longer walk, family members and friends started helping with money. That was what caused the delay in commencing treatment..."*

"... how would I have cope? If not for someone I never knew before just offered to sponsor my son's treatment!..."

A father: *"...since we started treatment, a cousin we were not so close before would wire money in my account at the end of every month to assist with my son's treatment, as if I was on salary..."* Money and prayers topped the list of much appreciated support received which helped them cope with the child's treatment; others were caring for other children at home while mother was on admission with the sick child, hospital visits, and few parents acknowledged students' donations of blood for transfusion. A mother: *"... my church people have helped us much, their prayers and frequent visits keep us going and strengthen our faith in God who we know will heal our child..."*

Discussion

The diagnosis of cancer in a child is devastating for parents, and difficult for some to come to term with (Renner & McGill, 2016; Njuguna et al., 2015; Buckle et al., 2013). It is possible that the few parents who could not recall the diagnosis of their children who had be undergoing chemotherapy for at least three months, were yet to adjust to the reality of the situation they found themselves in (Naidoo et al., 2016; Maree, Parker, Kaplan, & Oosthuizen, 2015). On the other hand, the lack of clear information to parents from the healthcare providers about their child's illness at the time of the cancer diagnosis has been reported and calls for consistent counselling with caregivers to help them have a clear insight about the disease (Renner & McGill, 2016; Eke, 2019; Naidoo et al., 2016). However, this may also be a reflection of our cultural or religious practices, where one should not confess negative words.

In this study, all interviewed parents reported that they children had or were suffering from side effects of chemotherapy, and the ones they considered as most distressful for parents to handle, such as vomiting, refusing feeds, pain, and falling of hairs, have been reported in several series (Elcigil & Conk, 2010; Renner & McGill, 2016; Saifan et al., 2014; Curco, 2010; Twycross, Parker, Williams, & Gibson, 2015). On the contrary, in Malawi, side effects of the chemotherapy (nausea, vomiting) did not cause concern to any of the guardians, since they were seen as proof that the treatment is with "strong medicines", and this may be related to differences in cultural perception (Israëls et al., 2008). Yet, for the medical team, some of those symptoms, e.g., vomiting, hair loss, are often perceived as normal things to happen and minor side effects and thus should not be a main worry. Nevertheless, they have been identified as sources of distress thus, have the potential to become detrimental to the child's treatment as well as the mental wellbeing of the caregiver, who most often is the mother, like in the present study (Elcigil & Conk, 2010; Renner & McGill, 2016; Saifan et al., 2014; Curco, 2010; Twycross et al., 2015).

As primary caregivers, these mothers are mainly the ones in charge of taking the sick children to the hospital, being with them all the time, being the ones who talk with the doctors and manage any information, witness the treatment, and face all the difficulties that being in the hospital may represent. These duties have also been identified as a great source of distress for the Jordanian mothers of children with cancer, while in El-Salvador, mothers reported that their biggest pain was feeling responsible for what the child was undergoing through the cancer treatment in the hospital (Saifan et al., 2014; Curco, 2010). Furthermore, several authors found that the effects of the chemotherapy and painful procedures caused so much worries to many parents, as they made the child suffer much more than what was experienced with the sickness symptoms (Curco, 2010; Twycross et al., 2015). Seeing their child in pain was deeply distressing, and physically painful for some parents, while for others, the emotional pain of seeing their child in pain was the worst pain they experienced (Twycross et al., 2015). This shows that there is a direct relationship between the parents' quality of life during the event of childhood cancer and the child's quality of life during treatment, and reinforces the importance of assisting parents as they deal with the diagnosis and treatment of their children by appropriately introducing psychological interventions to the caregivers, as well as patients, as part of the child's physiological treatment (Elcigil & Conk, 2010; Njuguna et al., 2015; Kohlsdorf & Costa, 2012; Marcus, 2012). Moreover, being saddled with so much burden while constantly witnessing much suffering may overwhelm these mothers and predispose them to burnout, an emotional and behavioural impairment usually preceded by continued stress with inability to cope, which can ultimately alter their ability to care for others (Amery, Bunn, Lapwood, & Chowns, 2009; Beheshtipour, Nasirpour, Yektatalab, Karimi, & Zare, 2016).

This study revealed that cancer treatment posed a great financial burden on the parents, with worsening of their economic situation, and constituted a threat to compliance to therapy, which had been previously reported (Renner & McGill, 2016; Saifan et al., 2014; Naidoo et al., 2016; Njuguna et al., 2015; Curco, 2010). Even though fathers were few among the respondents, they were also deeply affected, with the financial burden being their main cause of stress after their child's health status, and were similar to what was found in other series (Saifan et al., 2014; Kohlsdorf & Costa, 2012). This is however understandable as fathers needed to continue with their employment to maintain income. The supports parents received, monetary and otherwise, became important factors in helping them cope with the exigencies of their child's treatment (Witt et al., 2010; Naidoo et al., 2016).

And the greatest support came from family members which is a strong force to reckon with in African settings, followed by church members than friends and colleagues (Renner & McGill, 2016; Naidoo et al., 2016). On the other hand, mothers in Jordan and Turkey felt socially isolated as their relationship with other people decreased, because of the child's treatment requirements and burden of care, which were not mentioned among mothers in this study (Elcigil & Conk, 2010; Saifan et al., 2014). However, identifying with one another while caring for their sick children in the hospital and knowing that they were not alone, facing similar circumstances as well as their personal faith, helped them survive their daily lives (Renner & McGill, 2016; Saifan et al., 2014; Naidoo et al., 2016; Njuguna et al., 2015). This buttresses the benefits of support groups formed by patients and/or their families (Elcigil & Conk, 2010; Naidoo et al., 2016). It is noteworthy that, despite their financial constraints, prayers were most important to the respondents in this study, rated above money, food, and visiting. This is in agreement with findings of many researchers who suggest that spiritual and social support for families are important in the treatment of childhood cancers and strong pillars to coping, thereby making their representation in the multidisciplinary management team very important (Renner &

McGill, 2016; Naidoo et al., 2016; Kohlsdorf & Costa, 2012; Amery et al., 2009).

Conclusion

This study highlighted the need for healthcare providers to consistently offer information to the mothers and the child in relation to side effects of cancer therapy and best ways of coping with them. Creating awareness to stakeholders, including the government, to support families dealing with treatment of childhood cancer economically, emotionally, socially, and spiritually, to improve treatment outcome and quality of life of both parents and affected children is recommended. Limitations of the study: The small sample size in this study may not be representative of the general population of parents with children being treated for cancer.

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